

# Parents' role in enabling the participation of their child with a physical disability : Actions, challenges and needs

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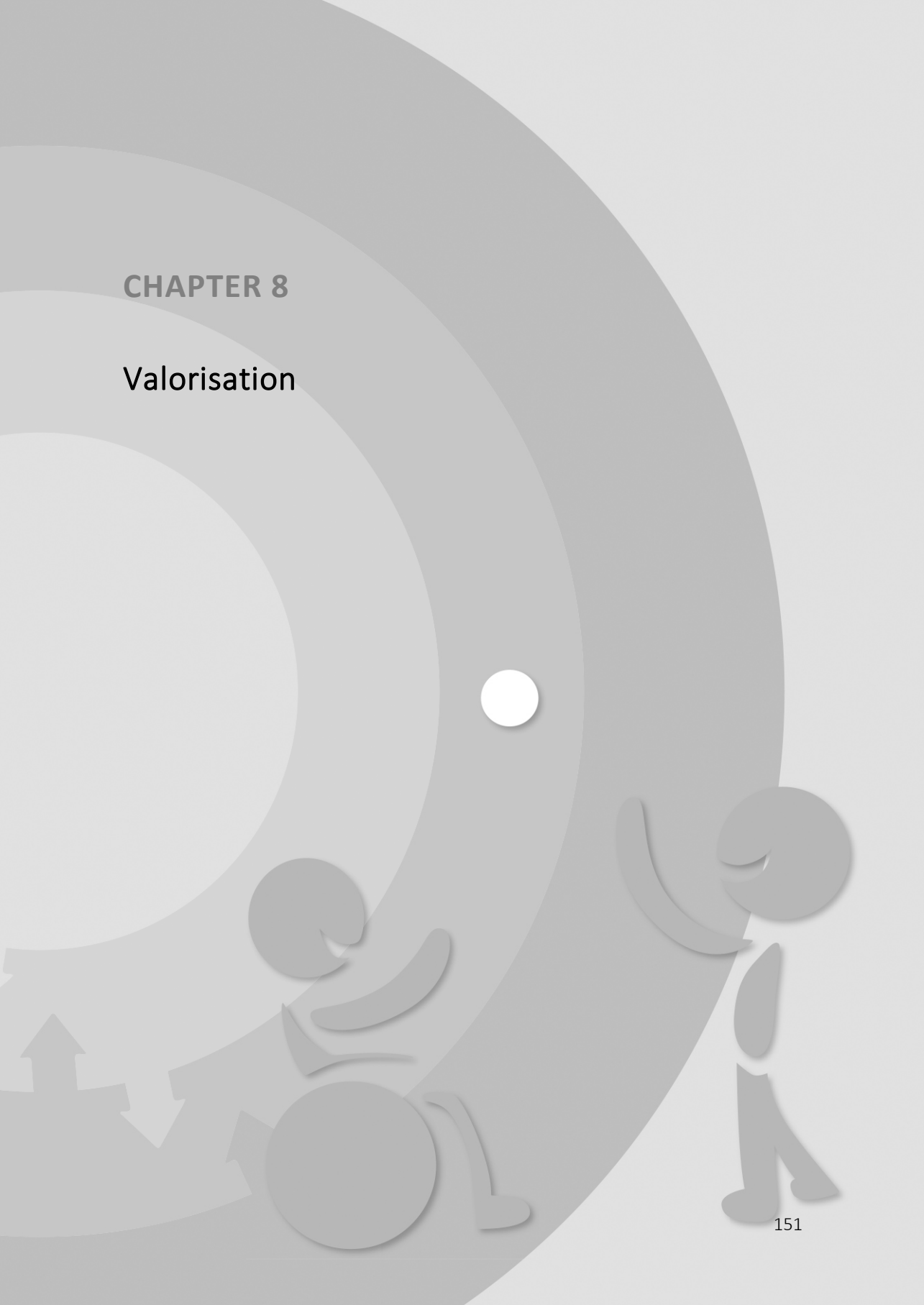
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## CHAPTER 8

### Valorisation





## Introduction

*“How to support my child in daily life?”* is an everyday question facing parents of a child with a physical disability. The experiences of these parents formed the point of departure for this thesis. Parents were and are seen as experts in their child’s life; they have many experiences in enhancing participation of their child in society, and consequently, are able to change, enable or use environments to support their child’s participation at home, at school and in the community. However, by some means parents of children with a physical disability do not always benefit from each other’s knowledge and sometimes miss the right support tools. Further, their stories are too little heard and understood. Working in co-creation with parents and a parent organisation following the motto “Nothing about us without us” has been thus a logical step for addressing this genuine societal problem.

In view of that, this thesis presents not only the scientific value of the studies as addressed in chapters 2-6, but also the societal value. Valorisation is the process of creating value from knowledge, by making this knowledge available and suitable for economic and social exploitation and its translation into products, services, processes or new business. This valorisation section addresses how the scientific knowledge could be transferred to and utilized in society; firstly, by looking at the relevance of the findings for actual societal developments and the role of the environment; secondly by providing examples of concrete innovative activities and products.

### Relevance of the findings and actual societal developments

The collective knowledge as presented in this thesis can, most of all, serve as a means for creating awareness. Awareness about the added value of user-involvement in research and awareness about the knowledge parents hold, actions they undertake, and challenges and needs they encounter in the social and physical environment related to participation of their child with a physical disability. The knowledge of this thesis is of relevance to local authorities and their community partners, school staff, rehabilitation professionals, health insurance companies and parents. They are all faced by the challenges posed by recent societal developments and demands in the Netherlands.

### Parents’ community participation

In this thesis, individual experiences and perspectives from parents of a child with a disability have been gathered and brought together into collective knowledge, available for parents to use for several purposes. Many parents of a child with a disability have a

need for contact with peers to exchange information. Contact with other parents with a child with a disability can offer support, can lead to meaningful advice and foster their community participation. It is assumable that the reforms in Dutch society will increase the need for support among parents, given that parents are increasingly expected to solve problems themselves [1].

A recent report [2] showed that parent organizations, like BOSK, have the impression that parents are frequently looking for written information on websites, either in parents' organisation magazines, or through advice forums on internet, either from people in their own social network. Furthermore, the report states that these parents are currently insufficiently able to share their experiences and in this way do not benefit from each other's knowledge [2]. Moreover, there are too few possibilities for parents to have their voices heard in the world of politics, care, education and research. Parents' community participation could rise to a higher level, where joint decision-making takes place regarding policy making or other relevant topics. This thesis provides a source of collective knowledge available for parents to learn from other parents' experiences, to reflect on their own challenges and needs and, by reading about the actions of respondents, to feel confident in being meaningful in enabling their child's participation. The explanation and description of user-involvement can encourage parents of children with a physical disability to play an active role in research or other fields of society.

### **Local authorities and community partners**

This thesis shows examples of parents' interactions with local authorities and community partners. The Social Support Act and the Youth Act have a big impact on Dutch society and the role of the local authorities and community partners [1]. The goal of the Social Support Act is that everybody – old and young, with and without a disability, with or without problems – can join in social life. Many people can join without help, but others need help and support, or a stimulating environment. Family, friends, social networks and organisations are believed to offer their help to a significant extent [1]. The new Youth Act, active from 2015, stipulates that local authorities will be responsible for all youth care services. The new youth care system should be more efficient, coherent and cost-effective. A focus on prevention, youth's and parents' own capacities, and a better cooperation between professionals must lead to a decrease in the use of the specialised services [1].

Because of these reforms, local authorities are supposed to shift to a "need led approach" leading to many challenges [3]. They have to organize collaboration between community partners to create a uniform vision and a coherent approach to care and

support [4]. Their employees need to develop competencies to understand the needs of clients and the social infrastructure and abilities to empower them [3]. In relation to children with a disability, employees are supposed to be capable of activating, restoring and strengthening the capacities of children, youth, parents and their social environment in order to solve problems [1].

This thesis can serve as a source of inspiration and learning for local authorities and the community partners (e.g. sport clubs, health and welfare organizations) involved in enhancing participation of children with a disability to understand the perspective of the parents on:

- their needs related to participation of their child with a physical disability
- the kind of problems their child with a physical disability experience in participation;
- the kind of problems they come across in contact with the employees;
- the kind of support they are looking for;
- how many and what kind of actions they (already) undertake to support their child with a physical disability;
- the lack of cooperation between stakeholders in the field of children with a physical disability;
- the possibilities of involving parents as experts in policy decision-making.

### **Inclusive education**

Parents through the findings of this thesis show their appreciation as well as their concerns with inclusive education. Inclusive education is a rather new development in the Netherlands [5]. An important facilitator in developing education that is more inclusive is the presence of curricular expertise and resources in schools. Leadership and involvement of school leaders, parental involvement, involvement of the pupils themselves, support (internal and external), a flexible curriculum and the willingness, knowledge and skills of the teaching staff are often mentioned as important facilitators for inclusive education [6]. A part of the challenge for educators is to involve parents in their daily work and to acknowledge their expertise [7]. Oberon [8] highlights the importance of creating equal partnerships between parents and the schools. Schools need to formulate how they envision parental involvement, what they expect from parents and what their own role is [9].

This thesis can serve as a source of inspiration and learning for school staff to understand needs, actions and challenges of parents with a child with a physical disability. Parents do undertake many actions to enhance participation and are experience experts. This thesis can raise awareness among school staff of the importance of accepting the perspective of parents on several levels of decision-making.